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Interim

INTERIM REPORT

IRVIS COMMITTEE ON SICKLE CELL ANEMIA

member of

GOVERNOR'S HEALTH TASK FORCE

COMMONWEALTH OF PENNSYLVANIA

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This document is an interim report of the Committee. It represents a working draft and is subject to revision before final adoption by the Committee. The final report of the Irvis Committee on Sickle Cell Anemia will be presented to the Honorable Milton J. Shapp, Governor of the Commonwealth of Pennsylvania, and to the Honorable K. Leroy Irvis, Member, House of Representatives of the Commonwealth of Pennsylvania, on May 1, 1973.

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FOREWORD

On behalf of the Irvis Committee on Sickle Cell Anemia, it is my privilege to present to the Honorable Milton J. Shapp, Governor of the Commonwealth of Pennsylvania, and to the Honorable K. Leroy Irvis, Member, House of Representatives, Commonwealth of Pennsylvania, this interim report. The report is the result of eleven months work conducted between February 9, 1972 and December 31, 1972, by a group of interested professional and lay citizens to assist the Commonwealth of Pennsylvania to confront the challenge of the problems and concerns manifested by many about sickle cell anemia.

The study report will reveal the extent of the problem, the intricacies and extent of involvement and the need for a coordinated effort beginning at the state level, to offer guidance and direction for planning programs about sickle cell anemia. We are fully aware of the complexities and complications posed by these revelations.

The report is a call to action—for government; public and voluntary health, education and welfare agencies; and the citizentry. It is imperative that the recommendations of the Committee be implemented immediately.

The effort to study facets of sickle cell anemia and to prepare this report has been a tremendous investment in time and money by the members of the Irvis Committee on Sickle Cell Anemia. For this has been a study that we have done ourselves. This tremendous enterprise involved all professional and lay members of the Committee, who participated in numerous meetings at their own expense or at the expense of the agencies or institutions for which they are employed. The individual and collective interest of the members of the Committee

...fully was to bring some order out of the chaos which exists concerning sickle cell anemia. The report represents a culminating synthesis of this interest.

In preparing the report, the Irvis Committee on Sickle Cell Anemia has reviewed existing literature on sickle cell anemia; interviewed lay and professional people on local and national levels interested in sickle cell anemia; heard presentations given by experts in the field; and conducted surveys to accumulate its information and to arrive at its conclusions and recommendations. The Irvis Committee on Sickle Cell Anemia does not claim to have produced a definitive work, but one to fill a critical void which currently exists. The result is an analysis of sickle cell anemia in Pennsylvania.

The report in no way purports to be judicial but does acknowledge that it is a syllogistic argumentation of a pioneering investigation and should command the support of the Governor's Office, the Legislature and the public, having been prepared by competent and capable professional and lay members of the Commonwealth. The document is bound to excite considerable discussion for the Committee will have failed if its report does not provoke discussion.

Finally, I should like to add that the great devotion to combating sickle cell anemia and to human values by each member of the Irvis Committee on Sickle Cell Anemia, as well as by my secretary, and the Public Relations Department of the Vice Chancellor's Office, Schools of Health Professions, University of Pittsburgh, is viewed by the Chairman as a strong motivating force in the preparation of the report. Collectively, the Task Committee report displays a fine combination of analytical power and institutional insight in an extremely controverted area. The report stands out as a monument to intellectual honesty, fine scholarship and objective presentation.

William R. Montgomery
Chairman

CONTENTS

NATURE OF THE PROBLEM

Chronic illness already is America's number one health problem and as new treatments are developed, the lives of persons with chronic illnesses will be extended. Progress and extending life expectancy has been a direct result of strong financial private and public support for research and demonstration programs. While many nationwide organizations supporting specific disease entities have received broad-base financial support from the public, sickle cell anemia has experienced very little support. Local groups have been organized to dramatize the need for care of the sickle cell patient and some research has and is being done on sickle cell anemia.

The approach to planning and providing services to patients and families of sickle cell anemics has been done in a piecemeal manner, resulting in duplication, overlapping and disorganization. Additionally, throughout the State, there has been an increase in the interest of numerous agencies and organizations toward developing education, screening and counseling programs about sickle cell anemia. This unusual interest manifested by so many individuals and groups to develop programs on education, screening and counseling on sickle cell anemia has resulted in a plethora of mininformation being thrust upon the community.

There is little know of the theoretical framework and the practical application of knowledge toward aiding the sickle cell patient or counseling the sickle cell trait client. Currently, there is not sufficient information to provide supportive services for the numerous counseling programs that exist throughout the State.

There are no standards, guidelines or regulations governing what should or should not be done in the provision of such services.

While it is commendable that the federal government has developed an interest in sickle cell anemia, there is little question that an availability of federal funds markedly will contribute to a further fragmentation of programs and a compounding of the existing problems of inadequate education and screening and counseling programs that have emerged in our communities. Despite the obvious effect of thrusting massive screening programs upon Black communities throughout the State and the lack of understanding of the psycho-social impact upon the community and upon family and individual stability, many local groups have seized upon sickle cell anemia as the "new ghetto hustle" with the goal to "rip off money". Ostensibly, funds are being solicited for the benefit of "striking out the deadly disease— sickle cell anemia" by many groups and organizations throughout our State. Government, corporations, organizations and individuals donate substantial contributions to local groups and institutions without regard for the negative impact and implicit destructiveness of screening programs or an accountability in the use of the funds.

Emphasis on mass screening for sickle cell trait indeed is a problem. Reports have been received that have resulted in job loss to Blacks; insurance policy cancellations; assignment of other physical problems to sickle cell anemia; public exposure of information about persons with sickle cell trait; and family disruption because both parents have normal hemoglobin and the S or C trait is present in the child. Clearly, there is a need for a reexamination of the purposes and the objectives of education, screening, and counseling programs.

For many years some have expressed concern regarding the inadequate services furnished to children with sickle cell anemia. Questions have been raised about the high costs of medical care for children afflicted with the disease; the need for supportive services for the patient and his family; community resources requisite to provide a program of comprehensive patient care; and the adequacy or inadequacy of educational programs on sickle cell anemia for the community.

Sickle cell anemia is no different than many diseases that handicap other children. Advances in medical science mean a longer life, and chronic complications will continue to affect the patient as long as he or she might live. The sickle cell anemia patient's illness currently cannot be cured or arrested. He must learn to adjust and live with his condition for the duration of his life. He will worry about the frequency of illness; continuing his education, and his capability to work, to earn an income or to learn a trade.

The sickle cell patient needs a wide range of facilities and services from professionals, technicians, and paraprofessionals, providing a continuity of care. Sickle cell anemia is a long-term illness and with few services currently available to the patient and his family, increasing chronicity of the illness results. The family, the community, and most specifically the taxpayer, must assume some financial responsibility for care of sickle cell anemics.

Accordingly, the Irvis Committee on Sickle Cell Anemia was created and charged with the responsibility to develop a plan on Sickle Cell Anemia for the Commonwealth of Pennsylvania. (See Appendix I)

COUNSELING

The life expectancy of a patient with the severe form of sickle cell disease is shorter than average. These years are characterized by frequent and traumatic periods of hospitalization, restricted activities, loss of school and work time, all of which is even more devastating to the patient when compounded by constant pain and fatigue.

Detection and diagnosis of the severity of sickle cell disease in a patient is vital, as is treatment, research and education. Identification of the extent of the disease in any given population and identification of the people involved so that they may receive care are important components to a life-sustaining direct service system.

The Committee on Counseling of the Irvis Committee for Sickle Cell Anemia wishes to propose and emphasize here the strategic importance of counseling in the above mentioned direct service system to sickle cell anemia patients and their families.

In the process of reviewing sickle cell anemia disease materials and publications, many references are made to Genetic Counseling and its importance to the clinical diagnosis and treatment of sickle cell anemia. We advise that Genetic Counseling is only one part of what should be a deliberate plan of total counseling which will encompass:

1. Genetic Counseling
2. Referral Counseling
3. Employment Counseling

4. Rehabilitation Counseling

5. Inter-disciplinary group counseling

6. Educational Counseling

7. Pre-clinical, clinical and post clinical counseling for patient and family

8. Intervention Counseling

To use a Irvis Committee member's definition coupled with some additions by the writer, "...counseling is the interpreting, advising, guiding, and utilization"... of factual information as it applies to the affected individuals and groups by a knowledgeable and skilled counselor.

Be not mislead, the above is not intended to be an official definition of counseling for sickle cell anemia by this Committee, but only an example of views on what counseling might be.

Counseling as a part of a planned and coordinated delivery system of skillful services to sickle cell anemia patients or sickle cell anemia trait individuals and their families has been implied and hinted at in many quarters of the Commonwealth of Pennsylvania and throughout the United States; however, we don't really know what it is, what it must do, and by whom it will be done.

We charge the Governor of the Commonwealth, his Health Planning Council, the State Health Department and all other divisions necessary in the legislative, judicial, and executive branches of Pennsylvania State Government with the opportune tasks of looking at this problem of definition and its ramifications.

This Committee would like to offer the following as areas for consideration:

1. Specific designated centers for training counselors.

2. A training curriculum for counselors.

3. What academic excellence is necessary for counselors?

4. What disciplines afford personnel for counseling?

5. Who will do the training?

6. Are training skills for counseling in other fields transferable to sickle cell anemia counseling.

7. Cost and financing of training and employment of counselors (this factor should be seriously considered before another state appropriation is passed by the State Assembly for monies to a sickle cell facility in Philadelphia).

Counseling

"The National Association For Sickle Cell Disease, Inc., notes that,'Genetic Counseling for carriers of the sickle cell trait is an essestial accompaniment to detection services.' The Association currently is seeking funds to develop four training sites around the country for lay, as well as professional, persons involve in counseling. The basic problem, at present, is that little has been done in this area. What is now commonly referred to as counseling is, in essence, patient education regarding "Do's" and "Don't" about the disease, sources of help in the event of crisis, etc. The creation of an effective counseling methodology that focuses on genetic factors such as selection of marital partners, advisability of having children, etc., effectively has not been treated. It ultimately will be necessary for the Committee to take a position on this issue in regard to the development of training centers for counseling and the nature of the information provided."[1]

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[1] Quote from Irvis Committee Comprehensive Care Report 12/7/72.

CHARGE

The Education/Communications Task Force has defined its charge as: 1) an indepth study of the kinds of information being disseminated by sickle cell anemia projects throughout the State of Pennsylvania, and the kinds of education or training programs being utilized by these projects for their staff or volunteers; and 2) the development of recommendations which would assist in the alleviation of some of the problems found in these two areas.

METHODOLOGY

The Task Force's approach has involved a three-fold process. First, an attempt was made, beginning August 1972, to ascertain the existence of all sickle cell anemia projects being implemented, or planned, in Pennsylvania. A questionnaire was developed and circulated to all the Comprehensive Health Planning 314 (b) agencies in the State, requesting information on all known sickle cell projects. To date, some 25 to 30 projects have been located and responses number approximately 22.

The Task Force is now studying these questionnaires, as well as all literature being circulated on sickle cell anemia, in order to assemble a listing of problem areas. These will be discussed at the next meeting of the Task Force.

Thirdly, once problem areas have been identified, the Task Force will attempt to develop recommendations which, if adopted and implemented, could provide a policy for use by all projects in designing their public information and educational programs.

TENTATIVE CONCLUS

Thus far, the Cor
information being diss
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logically harmful to the
indiscriminately circul
regionalized information
other aspects of diagno
dination and the idea of
persons involved in the

The Task Force will
group's final report shou
minimized.

COMPREHENSIVE HEALTH CARE

This report is addressed to the question of comprehensive health care in the area of sickle cell anemia. It offers some general guidelines and recommendations considered particularly relevant to issues of standardization and uniformity in the varying programs and activities which have proliferated across the Commonwealth within the past several months. There are two fundamental problems which serve as the premises for this document. First, sickle cell anemia programs, as the result of increased publicity of the disease, have suddenly become the "in" thing to do. Secondly, and perhaps most important, many programs are fragmented and ill-planned, resulting in services of questionable quality. In many cases the resulting impact upon the patient and upon the public has been a negative rather than a positive one. In what can only be regarded as a preliminary effort at this point, this report attempts to highlight some of the central issues conducive to good patient care. (Appendix)

Accordingly, the objectives of this document may be stated as follows:

1. To stress the need for a more comprehensive approach to patient care.

2. To emphasize quality of care considerations in patient care.

3. To identify means of better integrating sickle cell programs into the mainstream of the health care industry.

4. To emphasize the need for expanded services and better coordination among servicing agencies and institutions.

5. To emphasize the need for intensified professional education and in-service training about sickle cell anemia.

6. To stress the need for more accurate public information.

Comprehensive health care is a problem in its own right and is in short supply for most income classes and health problems. The problems of sickle cell anemia compound this fact. It seems appropriate, therefore, that while efforts to improve programs for sickle cell anemia are necessary, dual attention also must be directed toward increasing and expanding the supply of general cimprehensive care resources. Progress in the area of sickle cell anemia is dependent upon the latter.

The remaining components of this report are grouped into two broad categorical areas: Basic Functions and Supportive Functions. The first area discusses patient care services. The second presents some related factors of a supporting nature.

I. BASIC FUNCTIONS

There are four major service activities comprising the category of basic functions. They are screening, counseling, follow-up care, and health education. (See Appendix) These activities are directed at two fundamental objectives:

a. To ease the discomfort and trauma of patients with disease through an effective and systematic treatment plan.

b. to initiate steps directed toward diminishing the incidence of disease through preventive health education.

Screening

The experience with screening programs has raised the question of the desirability and the usefulness of large scale mass screening programs. A shift toward more selective screening, i.e., particular age groups, or women of child-bearing age, as initial priorities has been adopted by some operating programs. The

critical point here is that screening programs are essential to a comprehensive care plan. The scope or volume of screening, however, should be planned in accordance with the agencies' ability to offer follow-up counseling and patient care. Programs organized solely for the purpose of screening activities should be discouraged.

Secondly, screening methodology is an area in need of standardization. The two principal methods, sickle-dex, and electrophoresis enjoy varying levels of appeal and application. However, within the medical profession, there is some concern that sickle-dex is a less accurate method which produces a higher incidence of false positives and false negatives.

Recommendations

1. Mass screening programs should not be encouraged. Preference should be given to programs which offer a smaller but permanent type of screening activity. In no case should screening be initiated unless there is a demonstrated capability for counseling and follow-up patient care.

2. Where screening activities are initiated, they should be related to patterns of service available through existing or newly developed health care facilities to allow patient access to other necessary types of care.

3. Electrophoresis should be the preferred screening methodology. While it is a more expensive procedure, the qualitative superiority to sickle-dex is an important patient care consideration. Sickle-dex is not conducive to detecting other relevant hemoglobinopathies.

Counseling

The National Association for Sickle Cell Disease, Inc., notes that, "... counseling for carriers of the sickle cell trait is an essential accompaniment to detection services." The Association currently is seeking funds to develop four training sites around the country for lay, as well as professional, persons involved in counseling. The basic problem at present is that little has been done in this area. What is now commonly referred to as counseling is, in essence, patient education regarding "Do's" and Don'ts" about the disease, sources of help in the event of crisis, etc. The creation of an effective counseling methodology that focuses on genetic factors effectively has not been demonstrated.

The pamphlet entitled, "Guidelines for Counseling Job Corps Members With Sickle Cell Trait", available through the National Job Corps Center, offers a useful protocol for patient counseling. Among the more significant recommendations offered in this report are:

1. An effective counseling component must be an integral part of any comprehensive care program.
2. Uniform training for all counselors should be observed. There are no particular academic requirements, however, training for counselors should include mastery of the content of the above pa pamphlet and the ability to function effectively with it.
3. Clear limitations of the boundaries of the counseling role should be established. At no time should counseling serve to force or coerce the patient against his will.

PATIENT CARE

PROGRAM

Sickle cell diseases are genetically-determined red blood cell disorders which affect large segments of the American population. Although these diseases usually occur in the Black population, cases occasionally are found in the Caucasian population.

Sickle cell diseases occur in two forms.

The first form, sickle cell trait, occurring in about 8% of the American Black population, is a mild condition with no clinical symptoms. Occasionally persons with sickle cell trait are exposed to certain sets of environmental conditions and develop symptomatology.

The second form, sickle cell anemia, occurring in 0.2% of the American Black population, is a severe feneralized disease for which there presently is no cure. It is marked by exacerbations, leads to chronic disabilities, and life expectancy is shorter than average. Patients who survive into the third decade generally have milder symptomatology and are less disabled. Sickle cell anemia becomes manifest within the first four years of life and usually presents with major symptoms during the first two years of life. Exacerbations are commonly brought on by respiratory and intestional infections, and these causative factors require vigorous therapy if the exacerbations of the disease are to subside.

The expected number of cases of sickle cell anemia in Pennsylvania is slightly over 2,000. Continuous health care for these people is of the utmost importance if they are to achieve their optimum potential. Adequate nutrition; prompt medical

treatment of infections, exacerbations and other complications; [illegible] daycare centers, welfare agencies, school and vocational counseling. Comprehensive, continuous health care for sickle cell anemia patients [illegible] able to most of the population in need.

OBJECTIVES

1. To provide expert medical care for sickle cell anemia patients, sickle cell-hemoglobin C patients and sickle cell-thallesemia patients so that they may be alleviated, as far as possible, of the effects of their disease.

2. To encourage a close working relationship between the private physician and the sickle cell anemia center so that they jointly may provide care for the child.

3. To provide for periodic return to the sickle cell anemia center for continuing evaluation, consultation and direction of the course of the disease.

4. To provide needed medications.

5. To provide public health nursing and social work service.

6. To provide nutritional consultant services.

7. To arrange liaison with appropriate school personnel.

8. To arrange liaison with the Bureau of Vocational Rehabilitation.

9. To coordinate the efforts of private and public agencies, particularly those involved in sickle cell screening.

10. To conduct an educational program for physicians, nurses, social workers and school personnel.

METHODS:

1. Initiation of the Program:

The Division of Maternal and Child Health should establish a Sickle Cell Anemia Program in its Handicapped Children's Section which would initiate and administer part of this program. Although the Division of Maternal and Child Health is involved with persons twenty years of age and younger, and mothers, the Division should organize the clinics so that all age groups may be seen. Separate clinic hours may be established for the adult population, and the patient population twenty-one years of age and older should be administered by the Division of Chronic Diseases, after the program is initiated.

Sickle cell anemia centers should be established throughout the Commonwealth in areas of need and should provide expert medical care for patients. Hospital facilities should be used and the hospitals will be asked to donate clinic space and certain clerical and nursing services. In areas where independent health departments exist, they should be asked to provide public health nursing and social service work.

2. Consultant role of Sickle Cell Anemia Centers:

The centers also should serve as consultants to private and public agencies in the community to provide technical information as to proper screening procedures, patient education programs, and patient and physician educational materials.

3. Other functions of the Sickle Cell Anemia Centers and Sickle Cell Anemia Programs:

Liaison should be established, by the program and by the centers, with school authorities, with the Bureau of Vocational Rehabilitation, and with welfare agencies so that they may provide services to patients seen in the center. Procedure

should be developed, and personnel trained, to provide home care supervision of children with minor exacerbations or otherther complications of sickle cell anemia. Particular care should be directed toward providing comprehensive care and maintaining the same personnel in the center. The entire center operation should be patient-directed so that the patient and his family is taught, as far as is possible, to live comfortably with his handicap. Particular attention should be given to satisfactory communication of health personnel with low-income groups and to the establishment of centers in low-income areas of need. Education of personnel not directly involved in the operation of the clinic should be kept at a minimum.

The Sickle Cell Anemia Program should develop an administrative manual that the program and center activity may be administered effectively and efficiently and that services will be given in a dignified manner. This manual should indicate the specific resources needed to organize a sickle cell anemia center, the functions of these resources and their interrelationship and the method of reimbursement of the sickle cell anemia center by the Sickle Cell Anemia Program.

The program director should appoint a professional advisory committee composed of physicians knowledgeable in hematology to admise him on the professional content of the program. He also should appoint a consumer advisory committee, composed of two patients, or their parents, from each sickle cell anemia center to advise him on the content of the program and other matters of mutual concern. These two committees may, at certain intervals, have joint meetings.

4. Case findings:

Referrals to the program should be accepted from physicians, nurses, school authorities, social workers and community agencies. Where a private physician

exists his consent should be sought before the child is accepted in the program. All the diagnostic categories indicated in the PATIENT CARE OBJECTIVES should be accepted into the program and the program should establish technical criteria to be utilized in the diagnostic studies. The Sickle Cell Anemia Program should inform all interested public and private agencies of its existence and work with them to avoid duplication of effort. Sickle cell anemia centers should inform all public and private agencies in their patient catchment area of their existence and provide technical advice to these agencies to enhance case finding.

5. Personnel standards:

The director of each sickle cell anemia center shall be a physician, licensed to practice medicine in Pennsylvania, who is Board certified or eligible in Internal Medicine or Pediatrics and knowledgeable in hematology. Directors shall be appointed with the consent of the professional advisory committee; public health nurses and social workers who attend the clinic will have appropriate credentials from their organizations. Service coordinators, community agency representatives, and specialists in patient counseling will be required to demonstrate to the clinic director suitable competence to participate in the clinic.

All information relevant to patient personal data and circumstances obtained by state or local staff shall constitute privileged communications, shall be held confidential and shall not be divulged without the individual's consent, except as may be necessary to provide services to the individual. Information which does not identify the individual may be divulged.

6. Diagnostic services:

The program should provide such diagnostic services as are required to delineate the child's hematological condition. In most instances these diagnostic

services would have been provided before referral to the program. Follow-up hematological studies, as indicated, should be provided.

Diagnostic studies needed to delineate conditions not specifically related to sickle cell anemia, should be provided, subject to approval by the sickle cell anemia center and the Sickle Cell Anemia Program. Research studies should not receive fiscal support by this program.

7. Treatment Services:

Treatment services at home and in the sickle cell anemia center should be provided. Prescription medication relating to the child's hematological condition should be provided by the establishment of medication contracts with the pharmacy serving the clinic. Hospitalization should be provided, and third party insurance, Medicaid, and family participation, as applied in other Handicapped Children's programs, should be applied to hospitalization costs before the Sickle Cell Anemia Program can be utilized as a fiscal resource. Treatment services for conditions not relating to sickle cell anemia may be provided subject to budgetary limitations and the approval of the Sickle Cell Anemia Program and the sickle cell anemia center.

EVALUATION:

Evaluation of the Sickle Cell Anemia Program will be accomplished by:

1. Review of the Crippled Children's Service Report.
2. On-site visits by the program director and/or the regional medical director.
3. Review of the activities of each clinic in terms of types of patients seen and the management of individual patients.
4. Review of the program with the professional and consumer advisory committees.

Health Education

A fourth, but no less important, area is the subject of community health education. Two main components comprise this concern: (1) the patient community and (2) the remaining public. Some of the issues pertaining to the patient community have been mentioned. The concern here is to try to reach those persons who are not participating in a treatment program, or who fully are not aware that they have the disease, but may recognize the symptoms and should be encouraged to seek care. The second area requires that health information be directed to the remaining public that some understanding of the disease may be acquired. Again, the National Association for Sickle Cell Disease, Inc. notes that:

> The status of public information in the field of sickle cell disease is appalling. Currently, there appears to be as many versions of the basic facts as there are sources for them. Confusion, fragmentation, undue slanting, and over-dramatization of information are widespread. These factors are creating undue psychological problems for Black people throughout the country.

It is appropriate, therefore, for the Committee to consider the development of a univorm series of informational releases to attempt to clarify this confusion.

Recommendation

1. That the Committee petition the Governor's Health Task Force for funding to underwrite the development of an informational brochure to be developed under the guidance of the Pennsylvania Medical Society and the Keystone Medical Society.

II. SUPPORTIVE FUNCTIONS

There are two major areas from which supportive activities are obtained: (1) hospital and agency supports, and (2) professional association supports.

In reference to the former, the main concern is particularly that diagnostic procedures of a routine type initially be administered to all Black patients whether contact be through an emergency room, outpatient clinic, or routine in-patient admission. The concern here is that some hospitals fail to screen routinely for sickle cell anemia. To the extent that this becomes a regular institutional service, the need for mass screening and demonstration type projects will diminish. The goal is to integrate sickle cell anemia and its care into the mainstream of health care.

In reference to support from other health and related agencies such as neighborhood health centers, group practice facilities, private practice and ancillary welfare services, the same analogy applies.

Financial institutions such as the "Blues" and other insurances should be approached for inclusion of benefits to sickle cell patients in their subscriber programs. Of particular importance is the necessity for providing blood transfusion benefits. While, at present, some coverage exists, it must be expanded.

Finally, the area of ancillary support through agencies such as the Department of Public Welfare, Bureau of Employment Security, Bureau of Vocational Rehabilitation and others must be approached concerning the degree to which existing programs incorporate and provide assistance and benefits to the sickle cell patient.

The category of professional associations is fundamental to the whole effort. Here, two major groupings are at issue: the professional manpower groups, i.e., National Medical Association, National Dental Association, American Medical

VOCATIONAL REHABILITATION

PURPOSE

The Task Force on Rehabilitation has focused on a description of the services received by patients with a diagnosis of sickle cell anemia through the Bureau of Vocational Rehabilitation and the rehabilitation agencies in the Commonwealth of Pennsylvania. The interest of this study was to provide essential information on the limited services provided through vocational rehabilitation centers.

STATEMENT OF THE PROBLEM

Sickle cell anemia patients receive few vocational rehabilitation services. During the fiscal year July 1, 1971 to June 30, 1972, a total of 63,352 new referrals were received by the Bureau of Vocational Rehabilitation of the Department of Labor and Industry in the Commonwealth of Pennsylvania. (See Appendix) Of these 63,352 new referrals only 92 persons had a diagnosis of sickle cell anemia.

The 1970 Census reports that there are approximately 1,016,514 Blacks who reside in the Commonwealth of Pennsylvania based on the 1970 population. According to information received from the Pennsylvania Department of Health approximately 2,000 persons in the State of Pennsylvania should have a diagnosis of sickle cell anemia. Of these 2,000 individuals approximately 1,113 should have been referred to the Bureau of Vocational Rehabilitation. (The incidence of sickle cell anemia in the United States is reported to be found in one out of every 400 Black Americans.)

DEFINITIONS

Rehabilitation centers are those organizations whose primary emphasis is on physical restoration, such as physical medicine centers that are part of a hospital or of a separate medical institution listed by the hospital association. These centers also offer other services such as vocational evaluation, testing, and personal adjustment training. Some of these facilities are listed both as rehabilitation centers and as workshops.

Miscellaneous rehabilitation centers are those centers that usually specialize in inpatient care for specific types of disabilities. Their primary emphasis is on the treatment and social/vocational adjustment programs. Examples of these facilities are alcoholic and drug abuse centers, halfway houses for transitional living, and other type of miscellaneous services.

Workshops offer comprehensive rehabilitation services that include medical, psychological, social and vocational services with primary emphasis on the social and vocational aspects of rehabilitation. They provide evaluation, personal and work-adjustment training, training and occupational services, job placement follow-up services and activity centers and usually contain a sheltered workshop.

METHODOLOGY

The method used by the Task Committee on Rehabilitation to study the problem included a review of the literature; a questionnaire sent to all rehabilitation centers and workshops that provide services to Bureau of Vocational Rehabilitation clients and personal interviews conducted by Committee members.

In the survey, 16 questionnaires were sent to rehabilitation centers; 11 questionnaires or 68% were returned. Of the 11 agencies returning questionnaires, 2 or 18% provided during the past two years services to patients with a diagnosis of sickle cell anemia.

Twenty-six questionnaires were sent to miscellaneous rehabilitation centers; 18 or 69.1% of the questionnaires were returned. These questionnaires revealed that of the 18 returned only 3 or 16.3% of the miscellaneous rehabilitation centers provided rehabilitation services to patients with a diagnosis of sickle cell anemia.

Forty-eight questionnaires were sent to rehabilitation workshops; 42 or 87.5% of the workshops returned the questionnaires. Six or 14% of the 42 workshops reported that they provided services to patients with a diagnosis of sickle cell anemia.

DATA ANALYSIS

Analysis of the questionnaires is incomplete at this time. However, those questionnaires received revealed that many of the agencies had little knowledge of or prior experience working with a patient who had a diagnosis of sickle cell anemia. Moreover, in a significant number of the cases referred to those agencies that do provide services to the sickle cell anemia patient, sickle cell anemia was not the primary diagnosis for referral. For example: A review of 24 cases at a hospital with a predominately Black patient population indicated that none of the patients were admitted with a primary diagnosis of sickle cell anemia. In all cases, first admission to the hospital was the result of orthopedic complaints. Additionally, none of the sickle cell anemia patients were referred to the Bureau

of Vocational Rehabilitation. Another organization reported that, of 6 [illegible] of 11 anemia patients referred, 5 were referred because of mental retardation and [illegible] referred for physical defects. Interviews with physicians, administrators and supervisors of the Pennsylvania Bureau of Vocational Rehabilitation revealed that few of the interviewees were aware of the limitations or the rehabilitation needs of patients with a diagnosis of sickle cell anemia.

TENTATIVE RECOMMENDATIONS

1. Sickle cell anemia should be recognized as a legitimate handicap by the Pennsylvania Bureau of Vocational Rehabilitation.
2. Patients with a diagnosis of sickle cell anemia routinely should be referred to the Bureau of Vocational Rehabilitation for services.
3. Orientation programs about sickle cell anemia should be established for personnel in the Bureau of Vocational Rehabilitation, in rehabilitation centers and in miscellaneous rehabilitation centers and workshops.
4. Brochures and programs developed about sickle cell anemia should include the need for rehabilitation services.
5. Demonstration programs should be developed to study vocational rehabilitation services and the needs of patients with a diagnosis of sickle cell anemia.

TECHNICAL AND SCIENTIFIC AFFAIRS

Three challenging questions confronting the Irvis Committee on Sickle Cell Anemia, once screening has been conducted and the sickle cell trait established, are: what should be done with the information that has been collected; should research be conducted; and should screening be done if there is to be no research?

Generally, information about plans for sickle cell anemia research in the Black community either is not communicated or is interpreted in terms so technically sophisticated and grandiloquent that they are not understood. This lack of communication increases suspicion among the Black community which already harbors doubts of the sincerity of any research programs. Black hostility to research always has been present, articulated by both lay and professional Blacks. The "Black genocide" charge against many institutions and organizations has created an overt opposition to research. There is little doubt that the Black community, historically conditioned to a feudal social order, will reject any program, regardless of how beneficial it might be.

The Task force on Technical and Scientific Affairs supports the position of the Scientific Advisory Committee of the National Association of Sickle Cell Disease, Ind., regarding mandatory testing of school-age children:

> The Scientific Advisory Committee members were opposed on the grounds that it risks burdening the children with psychological problems far out of proportion to the benefits which would be achieved, particularly since this is certainly not the population at risk. Also, the low risk status of this group rules them out as a priority focus for expenditures of severly limited programmatic funds.[1]

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[1] Minutes of Scientific Advisory Committee of National Association for Sickle Cell Disease, Inc., June 24 and 25, 1972, New York.

Further, the Task Force supports the position of the Scientific Advisory Committee of the National Association of Sickle Cell Disease, Inc., [illegible] - datory testing:

> D. Statements Supporting Mandatory Testing Laws. The Scientific Advisory Committee is opposed to any advocacy of mandatory sickle cell disease testing legislation. The basis for this opposition can be summarized as follows:
>
> 1. Legislation should not be the first approach - those concerned should be properly informed and then given the opportunity to take the appropriate steps;
>
> 2. mandatory legislation threatens to infringe upon the already tenuous rights of Blacks - the most vulnerable group in the case.[2]

Accordingly, if research is to be conducted vis-a-vis the sickle cell trait, the Black community fully should be aware of and have complete knowledge of any research being planned. The Task force on Technical and Scientific Affairs strongly recommends a State policy on sickle cell anemia research and the use of human subjects in such research. This policy should be formulated by professionals and consumers from the Commonwealth of Pennsylvania representing the several disciplines and the Black community, in consultation with the Scientific Advisory Committee of the National Association of Sickle Cell Disease, Inc.

Dr. James E. Bowman, Professor of pathology and medicine at the Pritzker School of Medicine of the University of Chicago has, stated, "Sickle cell screening is being done by persons who are not familiar with the basic techniques

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[2] A Critical Review of Informational Materials Relating to Sickle Cell Anemia and Sickle Cell Trait; Sickle Cell Advisory Committee of the National Association for Sickle Cell Disease, Inc., October 1972, P.11.

of laboratory technology and who have no access to (and refuse) medical, hematological or genetic counseling expertise."[3] Numerous civic and social organizations throughout the Commonwealth are involved in screening programs. Many of these well-meaning groups have secured the services of volunteers to function as technicians in collecting blood samples. Unfortunately, many of these screening technicians do not have the necessary knowledge of or skill in the proper care of the collected blood samples. Clearly, the Task force feels that, in the interest of providing quality health care, any person participating as a technician in a screening program should have proper training. The Pennsylvania Department of Public Health should institute technician training programs and establish standards of qualification for all sickle cell screening technicians.

It is of value to consider the possibility of establishing controls for those persons in Black neighborhoods who will be participating as volunteer technicians in screening programs throughout the Commonwealth. It is questionable whether such persons without the necessary skills, knowledge or training should be involved in the extracting of bloods from individuals. The Pennsylvania Department of Health has a legal responsibility for the health of the Commonwealth population. It is imperative that the Health Department involve itself in determination of the quality of those persons who are to be technicians in screening programs throughout the State. Moreover, no screening program should be developed without having a physician or certified medical technologist in charge of or in consultation to the development of the screening program to insure that proper laboratory procedures are performed. It is not possible to provide quality health care if we do not introduce minimum standards for those persons who will be providing the technical services for sickle cell anemia programs.

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[3] James E. Bowman, Paper presented at the First Mental Health Conference on Sickle Cell Anemia, Meharry Medical College, June 26-28, 1972.

LEGISLATIVE RECOMMENDATIONS

1. The State Health Department should review and evaluate the laboratory methods used by sickle cell screening programs throughout the Commonwealth.
2. The Department of Health should determine whether the laboratories are functioning efficiently and effectively in performing laboratory procedures on blood samples that have been collected.
3. The Pennsylvania Department of Health should develop a mechanism for quality control of technical screening and laboratory staff.
4. There should be a central location where those persons serving as technicians are able to learn the most recent laboratory techniques in the extraction and storage of blood.

FUND RAISING

Humane causes attract advocates. Sickle cell anemia, as a disease requiring increased public concern, has attracted many persons to seek action roles on its behalf. The surge of interest in sickle cell anemia is an exciting and heartening experience for all who wish to reduce the suffering this disease produces. Some individuals are selling candy; others are taking door-to-door subscriptions; others still are placing donation containers in local businesses; prominent individuals are lending their name to fund raising efforts; and many television and radio stations are donating public service time to organizations who wish to increase their contributory funding. In contrast to these positive volunteer efforts, the fight against sickle cell disease has attracted many who would exploit it for their personal gain.

The Irvis Committee wholly supports the intent of the Pennsylvania Solicitation of Charitable Funds Act 1963 PL. 628 as Amended through Act 246 - 1972 (HB 1446, Page #2565).[1]

Legislative Intent

> The Act was amended to add a declaration that the Act is not merely a registry statute to require registration of charitable organizations, professional fund raisers and professional solicitors, but also to "regulate the soliciting of money and property by or on behalf of charitable organizations, fund raisers, professional solicitors and to require proper accounting for the use and distribution of said funds."

Registration of Charitable Organizations

> The Act requires that an annual registration statement be filed with the Department of State prior to any solicitation by every charitable organization which intends to solicit funds in the State.

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[1] Appreciation for analysis of the "Act" to Pennsylvania Department of Community Affairs, the Department of State, and to Community Services of Pennsylvania.

Registration Fees

The amended act increased the registration fee from $10 to $25 for any charitable organization which engages a professional solicitor or professional fund-raising counsel and/or spends 7% or more of contributions received for administration purposes, and received gross contribution of $25,000 or less from the public in the preceding year; and to $100 if such contributions were in excess of $25,000; requires disapproval of registrations for any organization for a false statement; or if the organization has been involved in a fraudulent enterprise; or if the solicitation would be a fraud on the public; or if total solicitation and fund raising expenses including allocable salary and overhead costs during any of the preceding 3 years, or for the projected year, have been or would be more than 35% of total pledges and contributions....

Fund Raising Practices

In keeping with the intent of Solicitation of Charitable Funds Act, as amended, this Sickle Cell Anemia Committee recommends that organizations allied with the cause of sickle cell anemia have the following characteristics:[2]

1. Have an active, voluntary governing body, with representation from diverse elements in the community, that would exercise effective control over the operations of the organization;

2. Faithfully adhere to a policy of non-discrimination with respect to age, sex, race, religion and natural origin with respect to the composition of its governing body, committees and staff and the persons whom it directly and indirectly serves;

3. Have been ruled exempt from taxation under Section 501 (c) (3) of the Internal Revenue Code and corresponding provisions of other applicable state or local or foreign laws or regulations;

4. Comply with all applicable legal operating and reporting requirements;

5. Operate with an annual budget approved in advance by the governing body;

6. Use ethical methods of publicity, promotion and solicitation of funds;

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[2] Fund raising practice statements based on information provided by the Easter Seal Society for Crippled Children and Adults, the National Information Bureau and the United Way of America.

7. Pay no commissions in connection with fund raising;

8. Have an annual audit by an independent public accountant whose examination is made in accordance with generally accepted auditing standards;

9. Issue an annual report to the public, including a financial report that complies with the "Standards of Accounting and Financial Reporting for Voluntary Health and Welfare Organizations" or other similar standards that may from time to time be recognized and approved by the organization's board of directors.

There is a tone of urgency and a desire for immediate reform and controls in the solicitation of sickle cell anemia funds. There must be continued vigilance to assure that exploitation of sickle cell anemia does not occur within the Commonwealth of Pennsylvania. If Pennsylvania is to be successful in its efforts to combat sickle cell disease within the State, it will be the lot of its citizenry, in the largest measure, to perform the difficult function of identifying those individuals and groups exploiting the cause of sickle cell anemia and, it will be the responsibility of the State to prosecute individuals in violation of fund-raising statutes. To do less would shortchange those who have contributed to a worthy cause.

FINANCING

The cost of patient care for any long-term medical treatment for a chronic anemia is expensive. The sickle cell patient and his family continuously are confronted with numerous bills for the expensive medical care that so frequently requires hospitalization. This care includes surgical, medical, hospital and pharmaceutical services. The cost of rehabilitation care, if necessary, must be borne by the patient or his family. Medical care insurance plans for the sickle cell patient have been cancelled increasing the financial burden of the patient, his family and, ultimately, the taxpayer. A Black earning a comfortable income, quickly will exhaust his or her resources in the care of a sickle cell anemia patient, and since most Blacks exist at the proverty income level, it is incongruous to talk about a Black family with a sickle cell patient member becoming bankrupt.

The severe limitation of funds for the medical care of sickle cell patients ultimately places the patient and his family in the public welfare sector. Costs for the medical care of sickle cell patients, therefore, will be passed on to the taxpayer. A well-planned and coordinated program for sickle cell anemia, with inclusion of patient medical care benefits, would reduce human and dollar waste.

Public Welfare and Public Health

Prepaid Health Plans

Irvis Committee on Sickle Cell Anemia

Task Force Committee Charge

The "Irvis Committee on Sickle Cell Anemia" is concerned with coordination, confidentiality, standards and procedures, in programs on sickle cell anemia in the State of Pennsylvania. Moreover, the "Committee" is committed to the principles of recommending guidelines and ways of reducing fragmentation, duplication and overlapping of sickle cell programs in Pennsylvania.

The current trend in the state indicates an increased number of individuals and groups becoming involved in sickle cell programs on education, screening, counseling, fund raising confusion and consequently poor planning which has resulted in a plethora of misinformation being thrust upon the community. Indeed some of the information has provided a forum for considerable debate. Very little information or knowledge is available on the complexity and durability of damage that might or is being done with poorly planned screening programs, inadequate counseling, educational programs and the lack of follow-up of contracts. Further, little if any attention has been given to patient care. Consequently, patient care is sporadic and not comprehensive. The utility and functioning of some programs in the State has not been a solid achievement.

The "Irvis Committee for Sickle Cell Anemia" will undertake the task of looking at the problems of sickle cell anemia concerning itself with six major areas:

1. Education and Communications
2. Costs
3. Comprehensive Patient Care

4. Counseling

5. Scientific and Technical Affairs

6. Rehabilitation

The "Irvis Committee on Sickle Cell Anemia" plans to prepare a report on the meetings conducted by each Task Force Group. What the Committee plans to do is perhaps unique in sickle cell anemia; however, it must be done. We are aware that we will be treading in a supersensitive area—challenging the very existence of sickle cell programs in the State.

The Task Forces are charged with the responsibility for:

1. reviewing reports, records (where indicated), legislation (federal and state), and the literature of programs on sickle cell anemia.

2. reviewing information on matters of policy, practice, procedures, standards, and confidentiality of programs of public and voluntary agencies.

3. assessing cooperation of public and voluntary groups interested in planning programs of sickle cell anemia.

4. identifying problems in public and voluntary organizations and recommending changes.

5. assessing patient care services and recommending ways of incorporating sickle cell patient care into comprehensive health care.

6. lending consultation services to voluntary groups who wish to be informed.

In taking on the aforementioned charge, our existence has been sustained [illegible] to the Governor by letter from the Honorable K. Leroy Irvis' office and the Chairman of the Irvis Committee on Sickle Cell Anemia in the hope of facilitating the task we are undertaking.

Needless to say, we are undertaking a difficult task, one which will possibly make us the butt of vehement denunciations by some individuals and groups in the state. Nevertheless, we should manifest an earnest Sunday-morning optimism. Indeed our report should stir the imagination to the extent that there will be some order emerging from the existing chaos.

William R. Montgomery
Chairman
Irvis Committee on Sickle Cell Anemia

May 22, 1972

Task Committee on Sickle Cell Anemia

Educational Task Force

PROJECT DOCUMENTATION SHEET

oject Name and Address	Type of Project (Screening, patient care, etc.)	Education/ Information Act. (list)	Samples (/)	Follo

QUESTIONNAIRE

INTIS COMMITTEE ON SICKLE CELL ANEMIA

Governor's Health Task Force

1. Program Name _____

Street Address _____

City, State _____ Zip Code _____

Business Telephone _____

2. Name of Program Head _____

Title of Program Head _____

3. Is your program administered by a larger agency?
_____Yes _____No (if no, skip to question 4)
If yes, what is the name of Administering agency _____

_____

Address _____

City, State _____ Zip Code _____

4. When did your program first begin?
Program began _____ _____
Month Year

5. How large an area does your program serve?
A. Number counties _____
B. Names of counties served _____

_____

_____

C. Approximate number of people _____
D. Other (specify) _____

7. What proportion of your total budget comes from the following sources?

Funding Source	Percent of total budget
a) Federal Funds	
b) State Funds	
c) County Funds	
d) City, Borough, etc.	
e) Corporations	
f) Foundations	
g) Contributions	
h) other (specify)	

8. What is the present size of the staff administering your program? How many are full time, part time, volunteers, etc?

Staff Position	Total Number	Full Time	3/4 time	1/2-3/4	1/3 or less
Director					
Doctors					
Case Workers					
Counsellors					
Nurses					
Volunteers					
Key Professionals or Outreach workers					
Clerical					
Consultants					
Other (specify)					

9. How are people informed of your program? (Check as many as apply; circle primary source of referral)

a) Agency referrals (e.g. public health, social service, etc.) ___

b) Local Community organizations ___

c) Family, relatives & friends ___

d) TV and radio announcements ___

e) Mobile units ___

f) Circulars and posters ___

g) Local newspapers ___

h) speaker's bureau ___

i) Telephone ___

j) Public announcements at organizational meeting ___

k) Outreach workers ___

l) other (specify) _____

_____

10. Fully describe your program in terms of the services that are provided.

a) Screening _____

_____

b) Conselling _____

_____

c) Patient Care _____

_____

d) Fund raising _____

_____

e) Research _____

_____

f) Other (specify) _____

_____

PUBLIC INFORMATION AND COMMUNICATION

11. Describe materials used for informational and educational activities, and if possible attach sample copies: _____

_____

_____

12. Describe any informational or educational activities already performed or being planned by your program (seminars, brochures town meetings, use of media, etc.) _____

_____

_____

13. List resource personnel utilized in these activities and their role (universities, consultants, outside experts, etc.) _____

_____

_____

PERSONNEL EDUCATION AND TRAINING

14. Describe any training activities performed or planned (orientation, inservice training, workshops, etc.) _____

_____

_____

A. Resource personnel utilized:

_____

_____

B. Personnel in charge of such projects (volunteers, staff, etc.)

_____

_____

C. Personnel receiving training

_____

_____

D. Person responsible for training projects

Name and title _____

Address _____

E. Describe training materials used and attach sample copies

15. List other groups that you are aware of that are involved in Sickle Cell Anemia projects:

_____

_____

_____

16. Would you be interested in cooperating with other groups sponsoring Sickle Cell programs?

17. Would you be interested in participating in a state-wide clearing-house for information on Sickle Cell Anemia?

18. Please add additional comments, recommendations, etc.

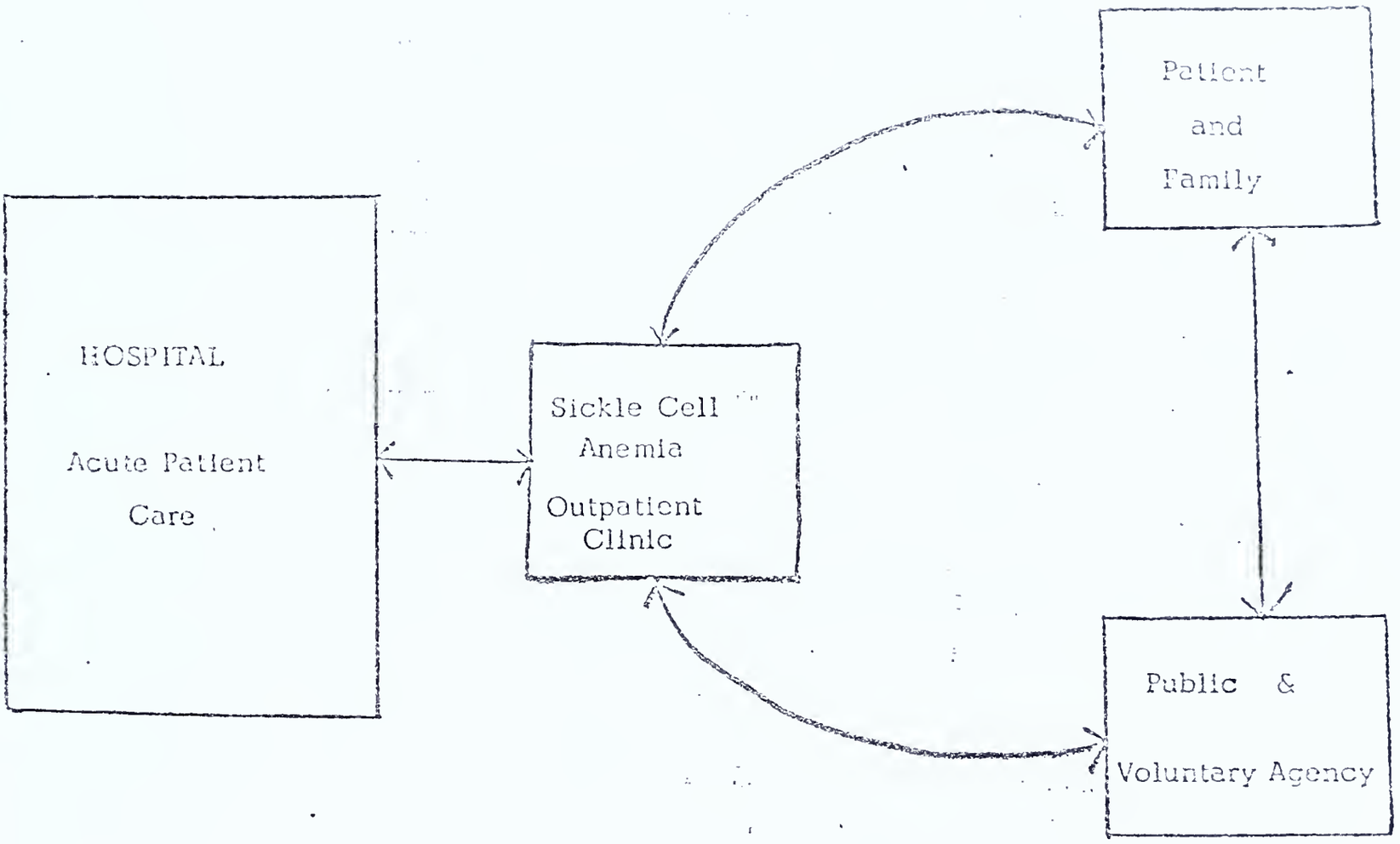
_____
Name of person answering questionnaire

_____
Title or position of person answering questionnaire

_____
DATE

COMPREHENSIVE CARE

(Continuity)



Patient Care

Sickle Cell Clinics

Quarterly, Semi-annual or Annual Checkup

Clinics' Staff

Pediatrician or Internist
Hematologist
Social Worker
Public Health Nurse
Laboratory Technician
Community Outreach Workers

Consultants' Staff

Psychiatrist
Dentist
Nutritionist
Ophthalmologist

Services

Speech therapy
Physical therapy
Occupational therapy
Pharmaceuticals
Orthopedic shoes
Braces
Cardiac care
Blood bank
Vocational rehabilitation
Dental care
Glasses

Iowa Committee on Sickle Cell Anemia

Governor's Health Task Force

Agency _____

Street Address _____

City and State _____ Zip Code _____

Telephone Number _____

Director _____

1. How many patients with a diagnosis of sickle cell anemia are currently engaged in vocational training in your Agency? No. _____

2. What is the source of referral of sickle cell anemia patients?

Bureau of Vocational Rehabilitation (Dept. L.& I.)	_____
Hospital	_____
Department of Public Welfare	_____
Department of Public Health	_____
State	
Local	_____
Physician	_____
Private Organization	_____
Other (specify)	_____

3. What is the age range?

Below 15	_____	25 - 27	_____
16 - 18	_____	28 - 30	_____
19 - 21	_____	31 - 33	_____
22 - 24	_____	34 and above	_____

4. How long have they been in your agency?

less than 12 months	_____	18 to 24 months	_____
12 to 18 months	_____	24 and above	_____
		(if above 24 months indicate specific number of months)	_____

5. How many patients with a diagnosis of sickle cell anemia have been involved in your agency's rehabilitation program? _____

6. What section of the state do the sickle cell anemia patients come from?

Southwest	_____	South Central	_____
Northwest	_____	Northeast	_____
North Central	_____	Southeast	_____

For what reasons were the sickle cell anemia patients in your agency referred for rehabilitation?

Orthopedic	_____	Visual	_____
Mental retardation		Psychiatric	_____
Speech	_____		
Other (specify)	_____		

Which services do you provide for sickle cell anemia patients?

Physical Therapy	_____	Skills Training	_____
Speech Therapy	_____	Medical Care	_____
Occupational Therapy	_____	Dental Care	_____
Education	_____	Psychiatric Services	_____
Job Placement	_____	Social Services	_____
Other (Specify)	_____	Psychological Services	_____

Is the emotional handicap around a specific problem?

Family	_____	School	_____
Marital	_____	Employment	_____
Other (Specify)	_____		

What types of individuals provide support services in your Agency?

Psychiatrist	_____	Psychologist	_____
Social Worker	_____	Aides	_____

What is the level of formal education of sickle cell anemia patients in your agency?

Up to 8	_____	Junior College	_____
9 to 12	_____	College	_____
Other (Specify)	_____		

If you have job placement services, how many sickle cell anemia patients have you placed?_____

Are they being placed in jobs for which they have been trained? _____

In what type of jobs are sickle cell anemics being placed ? (specify)_____

How are services to sickle cell anemics being financed?

Insurance	_____	Bureau of Vocational Rehabilitation	_____
Private	_____		
Department of Public Welfare	_____	Department of Public Health	_____
Other (Specify)	_____		

_____

(Name of person completing questionnaire)

Title_____

Date_____

Agency	Total Cases	Coll. or Univ.	Voc. School	Elem. or High School	Mental Hospital	General Hospital	Rehab. Facility	Public Welfare Agency	SS-Dis. Det. Unit	State Emp. Svc.	Other Pvt. Org.	Self-referred Person	Physician	Other Individual	Other Sources	Referral	Applicant	Plan Development	Plan Completed	Couns. & Guidance	Phys. Restoration	Training	Ready for Employment	In Employment	Service Interrupted	Closed - Not Accepted	Closed - Employed	Closed - After Plan	Closed - Before Plan
Total	19			2		1		7		1	1	4		3		1													
Coll. or Univ.	3			1				1				1																	
Voc. School	2											1																	
Elem. or High School	32			9	1	6	4	11	4		2	5	2	2	2	3	19	1	1	1	13	1				7	3		
Mental Hospital	2							1				1																	
General Hospital	8							1																					
Rehab. Facility	4																												
Public Welfare Agency	22			1		1		1				1																	
SS-Dis. Det. Unit	6							1																					
State Emp. Svc.	3	1																											
Other Pvt. Org.	2																												
Self-referred Person	12			1								1																	
Physician	2																												
Other Individual	6		1																										
Other Sources	3		1																										
Referral	4				1																								
Applicant	27		1																										
Plan Development	9	1	1	1										1															
Plan Completed	2																												
Couns. & Guidance	1																												
Phys. Restoration	13												1																
Training	1								1	1	1																		
Ready for Employment									3																				
In Employment										1																			
Service Interrupted														1															
Closed - Not Accepted	7			1	1			2		1		1	1																
Closed - Employed	3												1																
Closed - After Plan	1												1																
Closed - Before Plan	1							1																					